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JULY 2006

VOL. 11, NO. 7 • (pages 73-84)

Special Report: Recruiting, retaining hospice volunteers

Hospices develop a variety of programs to recruit and retain long-term volunteers

Volunteer hours skyrocketed at one hospice

Recruiting and retaining volunteers is likely to become a more challenging task as current societal trends continue, including the increasing time crunch many families experience.

A recent U.S. Department of Labor survey found that 45.6 percent of people who don't volunteer cited lack of time as their main reason for not doing so.¹ (See chart about volunteer statistics, p. 78.)

"We know that the national trend for volunteering is that people are having to work longer, they're not retiring as early, and they might be taking care of grandchildren, so our volunteer demographics are changing," says **Sandra L. Huster**, BA, director of volunteer programs for Covenant Hospice Inc. in Dothan, AL.

Hospices require considerable up-front, volunteer training, which might range up to 20 hours at some hospices, and this can be an even bigger obstacle to recruitment, says **Dedra Stodghill**, BS, volunteer coordinator for Abbey Hospice in Social Circle, GA.

For this reason, Abbey Hospice keeps the training to six hours, and it can be held on a Saturday or in the evening, spread over two days, she says.

After the formal training, hospice volunteers receive one-on-one training, which is more personal and directed toward helping them find a niche within the hospice organization, Stodghill explains.

"We try to send new volunteers out with a seasoned volunteer because it's difficult to walk into a patient's home the first time," Stodghill notes. "And when they're ready to visit their first hospice patient, we send them out with a staff worker."

Covenant Hospice requires eight hours of preparatory training for volunteers, covering all of the training components required by Medicare and the Joint Commission on Accreditation of Healthcare

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Organizations (JCAHO) of Oakbrook Terrace, IL, Huster says.

"Then we'll provide inservices for all of the other things that are good to know," Huster adds.

Hospice volunteers tend to be older than volunteers in general, Stodghill notes.

The Department of Labor's 2005 volunteer report found that 35 percent of the people who say they volunteer are ages 35 to 44, and 33 percent are 45 to 54 years, the two groups with the largest percentages.

But in an informal survey Stodghill conducted of hospices, the largest percentage of volunteers (35 percent) are age 65 and older, and the next largest group is in the 55-64 year age range.

"I think people are somewhat intimidated by hospice," Stodghill says. "But recruiting people to volunteer in hospice at younger ages helps dispel some of the myths about hospice."

In Florida's coastal Brevard County, about one-fifth of the population is retired, and more than

half of the hospice volunteers are over age 55, says **Marilyn Cromer**, MSW, LCSW, volunteer/bereavement manager at VITAS Innovative Hospice Care of Brevard County in Melbourne, FL.

"We have a number of volunteers in their 70s and 80s, and they have had years of volunteering," Cromer says.

It has been VITAS' experience that older hospice volunteers tend to stay with the hospice longer, Cromer adds.

The one sure-fire strategy to increase volunteer recruitment and retention is to devote a staff position to the role of volunteer manager.

Since VITAS Innovative Hospice Care of Brevard hired a full time volunteer manager, the number of hours volunteers donated to the hospice has skyrocketed, Cromer says.

The hours increased from 465 volunteer hours, valued at \$8,163, between Jan. 1, 2003, to Sept. 30, 2003, to 4,814 hours, valued at \$84,479, in 2004, Cromer says.

In the three months after Cromer was hired on Sept. 30, 2003, the volunteer hours were 453, valued at \$7,948, she says.

Cromer, Stodghill, and Huster describe some strategies hospices can use to recruit, retain, and diversify their volunteer base:

1. Show volunteers how they can find time for hospice training and service.

"One thing I have found very interesting is right after the holidays if I hold volunteer training in January or February, registration skyrockets," Stodghill says. "But when they do start volunteering, they say they don't have the time for it, or their interest falls off."

When people say they don't have time to volunteer, hospice staff could respond that volunteers don't have to give an abundant amount of time, Stodghill suggests.

"That's where we have to get creative and look within our organization to see what folks can do in short periods of time," she says.

"It's becoming more difficult to recruit volunteers who have time to visit patients once a week and who will remain volunteers for five years or longer," Huster says. "That's changed, and we're looking at episodic volunteering or one-time volunteering."

For example, a church might decide to provide one day of volunteer service to a hospice, so it's a good idea to keep a list of projects that need to be done, Huster suggests.

Hospice Management Advisor™ (ISSN# 1087-0288) is published monthly by Thomson American Health Consultants, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. First-class postage paid at Atlanta, GA 30304. POSTMASTER: Send address changes to **Hospice Management Advisor™**, P.O. Box 740059, Atlanta, GA 30374.

Subscriber Information

Customer Service: (800) 688-2421 or fax (800) 284-3291, (ahc.customerservice@thomson.com). **Hours:** 8:30 a.m.-6 p.m. Monday-Thursday; 8:30 a.m.-4:30 p.m. Friday, EST.

Subscription rates: One year (12 issues), \$399. Outside U.S., add \$30 per year, total prepaid in U.S. funds. Discounts are available for multiple subscriptions. For pricing information, call Steve Vance at (404) 262-5511. Missing issues will be fulfilled by customer service free of charge when contacted within one month of the missing issue date. **Back issues,** when available, are \$58 each. (GST registration number R128870672.)

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Editorial Questions

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A patient and caregiver might need help with raking their lawn, or another patient might need a ramp to be built to the front door, Huster says.

"Someone else would like a home-cooked meal, or our office might need sprucing up with some flowers planted outside," Huster explains. "We always have some projects on a list."

One year, a Harley Davidson motorcycle club called the hospice to offer to adopt a family for the holidays, Huster recalls.

"We told them of a family with three children, gave them the ages, and they covered Christmas for that family, including bicycles for the children," Huster says. "People often want to give, and sometimes we're not specific enough in how we ask for help."

2. Develop volunteer projects for non-traditional hospice volunteers.

Stodghill's small hospice survey's findings suggest that hospice volunteers are more likely to be older white women than are volunteers in general.

While the Department of Labor's volunteer survey found that 30.4 percent of volunteers are white, Stodghill's hospice survey found that 88.6 percent of hospice volunteers are white.

To diversify the hospice volunteer base, hospices could recruit volunteers at African American churches, Stodghill suggests.

Sometimes all that a volunteer recruiter needs to do is ask people if they would consider volunteering, she notes.

More than one-fourth of people who volunteer say they volunteered because someone in their group asked them to, so that works, Stodghill says.

"The other piece of the puzzle is we need to meet their needs," she says. "The African American community has to see how it will benefit them, and the same is true with men and any group that doesn't volunteer for hospice."

For instance, the hospice volunteer director could visit an organization like the Rotary Club and say, "You know what, I have a good opportunity for you," Stodghill says.

As a hospice's region becomes more diversified in its general population, it's time to take a look at adapting volunteer recruiting methods to meet this new challenge, she says.

"Here in Georgia, we have a growing Hispanic population, so I need to look at what I can do in my program to increase the Hispanic volunteer base," Stodghill says.

Also, hospice managers should think of volunteer work that might interest male volunteers

more than visiting patients, Stodghill suggests.

"We have had one volunteer who was very good about helping out patients with yard work and things like that," she notes.

Other volunteers might answer the phone, stuff envelopes, provide help with filing, help with the computer system, paperwork, and data collection.

VITAS has a volunteer who visits once a week to input data on the computer of all of the volunteer hours donated to the hospice, Cromer says.

"He won't leave until he finishes the task," Cromer says. "He has a sense of ownership for the job of recording volunteer hours, and the job has grown from one hour a week to four to five hours a week."

3. Provide social experiences for volunteers and show them appreciation.

Most hospice volunteers cite altruism as a chief reason for wanting to help out, Cromer notes.

They might be church-going people who have a sense of needing to give back to help the less fortunate, or they might be motivated by a belief in the mission of hospice because they've personally witnessed hospice at work, Cromer explains.

"Once they've jumped in and had the experience, they get a wonderful sense of satisfaction, and they say they get back far more than they give, and that's true of any hospice," Cromer says.

Hospice volunteers also thrive on having a bonding experience with each other, and this leads to a sense of connectedness, Cromer says.

"I think we have to promote that and recognize it and provide avenues to keep our volunteers connected with each other," Cromer says.

This can be challenging because hospice volunteers tend to not see one another during their volunteer service, so it's up to a hospice to provide social experiences in which volunteers can interact and bond, Cromer suggests.

This could involve an ice cream social, inviting volunteers to staff meetings, or holding other social events, she says.

"In the hospice arena, people do work in isolation, so for people who have that need for affiliation, we recognize that and offer opportunities for them to get together," Cromer says.

VITAS Innovative Hospice Care also shows volunteers appreciation through birthday cards and thinking-of-you cards when they are hospitalized or sick, Cromer says.

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Hospice creates volunteer ambassador to spread good news about hospice care

Ambassadors donate hundreds of hours each month

A regional hospice's community educators were challenged to cover 35 counties across two states, making it difficult to get the word out about hospice to health care providers and the community. So hospice managers decided to do something a little different to meet the need and created a position for volunteers who have skills in community outreach and public speaking.

Now, there are more than 150 volunteer ambassadors, which is what the outreach volunteers are called. They serve 11 branch offices at Covenant Hospice Inc., whose corporate office is in Pensacola, FL, says **Sandra L. Huster**, BA, director of volunteer programs for Covenant Hospice in Dothan, AL.

Volunteer ambassadors visit doctor's offices and speak with front desk staff, dropping off hospice literature; they speak to civic groups, faith congregations, and senior centers, educating people about Covenant Hospice, recruiting more hospice volunteers, and they represent the hospice at senior fairs and health fairs, Huster says.

"Out of the Dothan office there are 10 trained ambassadors," Huster says. "They meet monthly with community educators to plan and organize, and they have their own tote bags and materials."

Huster estimates that volunteer ambassadors each provide outreach services for eight to 20 hours per month, and they donate their mileage. Hard data are not yet available, but the hospice has seen an increase in volunteers, inquiry calls, and referrals since starting the program, she says.

"We piloted the program in Dothan and saw an increase in inquiries about hospice and referrals, and we knew it was something we wanted to share with all of our offices," Huster says.

Many of the ambassador volunteers are retired professionals, who spent their careers in work where they used related skills, including retired teachers, non-profit directors, medical profession-

"We call volunteers once a month to say "Hello," and to thank them for what they're doing, and to see how they're doing and if they have any questions or concerns," Cromer says. "We try to reach out on a regular basis."

Another way to show appreciation is to assist volunteers with transportation problems when these arise.

For instance, at VITAS, one volunteer who is in her 80s is unable to drive, so when she needed daily training for a week to become an office volunteer, another volunteer would pick her up and take her to and from the training session, Cromer recalls.

And another volunteer drives her to the office where she volunteers one day a week.

During National Volunteer Week in April, VITAS holds a volunteer party based on themes. This past year's theme was a Mexican fiesta, and it included a Mariachi band, Mexican food, games, and contests, Cromer says.

"Around Thanksgiving we have a covered dish dinner; at Christmas we have a holiday party, and once a year we have a picnic for staff and volunteers," Cromer adds. ■

Reference

1. Volunteering in the United States, 2005. United States Department of Labor. Dec. 9, 2005. Available: www.bls.gov/news.release/volun.nr0.htm.

als, and public relations personnel, she says.

"We had one woman who had been a director of volunteer programs for a large medical center, and her whole life's work was spent running large volunteer programs," Huster says. "We approached her with this idea and asked if she would be the team leader for a group of ambassadors, help us recruit and train and make assignments."

The woman accepted the role and has been key to the success of the program in Dothan.

The volunteers have developed strong loyalty to the hospice and the program, and they've bonded socially, often having ambassador volunteer lunch gatherings.

"Many see this as a chance to use their marketing skills, people skills, and speaking skills," Huster says. "They're needed and very viable, and they have a feeling of success about what they're doing."

The two-year-old ambassador program has had very low turnover, and it's enabled the hospice to attract volunteers who are interested in doing work that is outside of direct patient contact, Huster says.

"We really want to include young people in this too, and we are working with college and high school students who have an interest in this kind of experience," Huster says. "Several offices have access to college students in its town, and all of the offices are working with high school students who might volunteer as part of a youth group in a congregation or perhaps as a service group in a high school."

Volunteers coordinate the ambassador program, assist with training and education, and have taken ownership and pride in what they're doing, Huster notes.

"Educators share the big picture of what is happening, what are the challenges and needs we have now, and they help the ambassadors see how their work is part of the big picture and mission of the organization," Huster says.

Volunteer ambassadors receive two hours of additional training, including information about hospice admissions, specific cancer and non-cancer diagnoses, how hospices are reimbursed, and how Covenant is a not-for-profit hospice and will provide hospice services regardless of a patient's ability to pay, Huster says.

"The other message we wanted to teach our ambassadors and have them share with people is how to ask for hospice early in a person's end of life care," Huster says.

"We train our ambassadors to say that anyone can call and ask about hospice care for their loved ones," Huster adds. "Our ambassadors encourage early referrals and early admission to hospice care."

Volunteer ambassadors wear a Covenant Hospice badge when they hand out brochures and referral information.

"Each month, our corporate office provides talking points about our services, and we ask the ambassadors to help deliver these to doctors' offices," Huster says.

"Our educators are out on a regular basis too, but it expands their outreaches and increases the frequency of visits, helping to identify people who need information that our educators had never thought about before."

Ambassadors have their own ideas about outreach, and the educators listen to them, asking them where they travel in their daily lives and where they might meet someone who needs to hear about end of life care, Huster says.

A volunteer ambassador program is fairly easy to start once the training curriculum is established, Huster says.

Such curriculum could include the following:

- What is hospice care?
- What's unique about your hospice?
- How can someone access hospice care?
- How can someone support your hospice?

"You can tap your existing volunteers and get it going with those folks," Huster suggests. "It's not expensive to start when you already have materials available for community outreach."

While the idea of having volunteers assisting with community outreach and hospice marketing services might be a novel one for many hospices, it can be one of the best ways to promote hospice care, Huster notes.

"The volunteer ambassadors say that people are amazed that they were there giving their time to do this and were not getting paid for it," Huster says. "With the program, we're marketing and educating and inviting people to volunteer."

Volunteer ambassadors are given a script they can refer to, but the words can be their own. They are encouraged to make the ask at the end, saying, "I'm so glad you let me be here today; now let me tell you how you can be involved with hospice," Huster says.

"The best recruiter of volunteers is another volunteer," she adds. "We see a wonderful recruitment result of their efforts." ■

Who volunteers in general, compared with hospice

Data from this chart were collected by Dedra Stodghill, BS, Volunteer Coordinator at Abbey Hospice in Social Circle, GA, and the statistics include information from the U.S. Department of Labor's survey of volunteers in the United States, reported on Dec. 9, 2005, as well as data collected by Stodghill in a small and informal hospice survey.

Volunteers by Age

Hospices

16-24: 24%
25-35: 25%
36-44: 35%
45-54: 33%
55-64: 30%

DOL survey

16-24: 3.1%
25-34: 2.0%
35-44: 11.7%
45-54: 19.4%
55-64: 29.6%
65+: 35%

Volunteers by Ethnicity

Hospices

Caucasian: 88.6%
African American: 9.2%
Asian: 1.2%
Hispanic: 2.0%

DOL survey

Caucasian: 30.4%
African American: 22.1%
Asian: 20.7%
Hispanic: 15.4%

Volunteers by Employment Status

Hospices

Full Time: 23.3%
Part Time: 8.9%
Unemployed: 7.8%
Not in Work Force: 60.0%

DOL survey

Full Time: 29.8%
Part Time: 38.2%
Unemployed: 26.4%
Not in Work Force: 24.4%

Volunteers by Education Level

Hospices

Less than High School diploma: 6.0%
High School graduate: 28.8%
Less than 4-year degree: 35.4%
College graduate: 34.2%

DOL survey

Less than High School diploma: 10%
High School graduate: 21%
Less than 4-year degree: 34%
College graduate: 46%

Main reason for not volunteering in last year:

DOL survey

Burnout: 2%
Family responsibilities or child care problems: 9.3%
Health or medical problems: 15.2%
Lack of time: 45.6%
No one asked: 2.9%
No longer a member of the organization: 1.9%
Wasn't interested: 3.9%
Moved, lack of information, transportation or expense: 3.9%
No longer required, not relevant to current life situation: 4.9%

Volunteers by type of main organization

DOL survey

Civic, political, professional, or international: 6.4%
Educational or youth services: 26.2%
Environmental or animal care: 1.8%
Hospital or other health care: 7.7%
Public safety: 1.3%
Religious: 34.8%
Social or community service: 13.4%
Sport, hobby, cultural, or arts: 3.3%
Other: 3.5%

Hospice opened center to provide community with end of life planning

Hospice's census rose 59 percent with program

Hospices sometimes find it challenging to meet a community's needs in end of life planning and bereavement services, since these are only a small part of the services a hospice provides.

But there are many benefits to expanding this area of outreach, as one Virginia hospice discovered after it opened last year the Center for Hope & Outreach Services, a program where anyone in the community could receive bereavement services, counseling, assistance with end of life planning, and education about hospice care.

Blue Ridge Hospice in Winchester, VA, has found that an extension of community outreach and end-of-life planning has resulted in a 71 percent increase in its daily census, from 81 patients to 139 patients, since the center opened on Aug. 25, 2005.

"We're trying to educate the community and provide resources to them about the process of planning to make end-of-life decisions," says **Lynn Gray**, LCSW, director of clinical services.

The hospice opened the Center for Hope as an expansion of existing grief and life planning services, says **Pamela Richards**, LCSW, director of the Center for Hope & Outreach Services in Winchester.

For 25 years, Blue Ridge Hospice has provided grief support for people who have lost a family member in the hospice's care, Richards notes.

"We mail out grief support material every two or three months and offer individual counseling," Richards says. "What we've found is there are many people who needed more than that, and there are community members who would call us for grief support after someone they loved died suddenly and was not a hospice patient."

In just the past four years the number of calls for grief counseling have increased by nearly one-third, Richards says.

With a federal grant, the hospice opened the Center for Hope as a free-standing grief center that provides one-on-one counseling, family counseling, group counseling, and serves as a resource center where people can come in and get

materials on grief and loss, Richards says.

The center has been so successful from the start that the hospice made plans to open two more Center for Hope sites, she says.

"The center's reception is fun by volunteers, and we have two full-time therapists and a part-time bereavement counselor," Richards says. "We also have one spiritual counselor, who is employed by Blue Ridge Hospice."

Word has spread quickly about the center's services: through the first week of May, 2006, the center had received 529 calls from people who had experienced a loss and wanted help, Gray says.

The hospice's bereavement staff will screen calls to make the appropriate referral, Gray adds.

"As we continue to educate the community about our services and the word gets out about these services, the contacts grow and grow," Gray says.

"The local hospital refers people to us if they've had a loss in the emergency room," Gray adds.

"And, lately, long-term-care facilities have referred their staff to us after they experience the loss of a long-time patient."

When the center was initiated, hospice outreach staff made 300 community contacts in six months, spending an hour discussing the center's services with funeral home directors and others, Richards says.

To save resources, the center is located within a satellite office which is used by hospice staff.

"It's located in a 100-year-old home on Main Street," Richards says. "There's a curved banister, high ceilings, wood floors, and we turned the downstairs into two individual counseling rooms, a child's play therapy room, and a group counseling room that's located in an old living room parlor."

The atmosphere is cozy and comfortable, and there's always hot tea brewing. The waiting room is filled with resource material, and there's a lending library, as well, Richards says.

"It's a safe place to come and talk about your feelings," Richards says. "We have sound machines in every room by the door, and we've laid carpet and hung quilts, made by volunteers, on the walls."

Also the doors are solid wood, so the counseling rooms are soundproof, she adds.

Hospice clinical staff work in the upstairs rooms.

"The staff who work out of that office live in that area, and if there's some kind of traumatic

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- ◆ **Pamela Richards**, LCSW, Director of the Center for Hope & Outreach Services, Blue Ridge Hospice, 333 West Cork Street, Suite 405, Winchester, VA 22012.

death in the community, the next morning, the staff can talk about what's going on and be prepared for fielding phone calls from the community," Gray says. "They also might help local schools and police officers who might have responded to an emergency call."

Having the bereavement staff working in the same building as the clinical staff provides continuity, Gray adds.

The center's resource material has been translated into Spanish, and this has helped with outreach to the area's Hispanic community, Richards says.

"We have had a significant focus on the Hispanic community and have a growing number of Hispanic referrals now," Richards says.

"We are convinced the center has increased awareness of hospice," Richards says. "It was a great lesson for us about how a well-organized outreach program can help you get out and educate the community."

The center's grant funding has ended, but there's the possibility of more grant money, Richards says.

Meantime, the hospice is absorbing its costs into the general budget, she says.

The center accepts private insurance, as well as fees on a sliding scale, but it will serve clients regardless of their ability to pay, Gray says.

Family members of a hospice patient still receive bereavement services at not charge, but when someone is referred to the Center for Hope, there is expanded counseling that can be provided at a fee as small as \$15 for a session to people who cannot afford to pay more, Richards says.

"If they come here for end of life care and don't have insurance or resources, we still provide care, and it comes from the patient care fund," Richards explains. "We're always doing fundraising events for that patient care fund." ■

Can surrogates really know patients' wishes?

Just more than half of surrogates get it right

Making end-of-life decisions for incapacitated patients most often falls to surrogates chosen by the patients, or to next of kin. But a recent review of the literature indicates that surrogates are only slightly better than physicians at making decisions that the patient would make if he or she were able.

Terri Schiavo's dilemma—being the center of a struggle over end-of-life decisions between her husband, who Florida state courts recognized as her legal next of kin for decision-making purposes, and her parents—has prompted many Americans to sign living wills and talk to their next of kin about what end-of-life care they want or do not want.

But according to **David Wendler**, PhD, of the National Institutes of Health's Department of Clinical Bioethics, a review of studies that provide data on how accurately surrogates predict patients' treatment preferences indicates that while those discussions are certainly better than doing nothing, surrogates in the studies predicted patients' treatment preferences with 68% accuracy.

Surprisingly, they did even worse after discussing treatment preferences with the patient.

Surrogates get it right sometimes

The analysis, conducted by Wendler and colleagues at the National Institutes of Health and Johns Hopkins University, examined 151 role-playing scenarios that were presented to 2,595 patient/surrogate pairs.¹ The "patients" in some cases were healthy subjects asked to assume they were incapacitated and others who were actual patients not at the end of life.

In the studies, the next of kin or surrogate decision makers were asked to decide whether the patients would want certain medical interventions, often ones that physicians deemed

necessary to keep the patients alive. The patients were asked, independently, what their preferences would be.

A sample hypothetical scenario was: “You recently suffered a major stroke, leaving you in a coma and unable to breathe without a machine. After a few months, the doctor determines that it is unlikely that you will come out of the coma. If your doctor had asked whether to try to revive you if your heart stopped beating in this situation, what would you have told the doctor to do?” Patients and surrogates were free to choose to accept or reject the proposed treatment.

Leaving the decision up to doctors resulted in a rate of 63% accuracy at predicting what the patient would want. Surrogates or next of kin fared only slightly better at 68%.

Of the 16 studies reviewed, 12 assessed the errors surrogates made when they misjudged patients’ preferences. Three studies found that they erred by choosing interventions that the patients said they would not want. One study found that surrogates erred by withholding interventions the patients would want, and eight studies found no consistent trend in surrogates’ miscalculations.

The studies showed only one percentage point difference in the accuracy of patient-chosen surrogates (69%) and legally assigned surrogates (68%).

“In general, we thought the way to explain people not being as accurate as you hope they are was that they are unwilling or reluctant [to make the decisions]; but we found you really can’t say one way or the other,” says Wendler.

Talking about preferences doesn’t help

It would be natural to assume that if patients and their surrogates talk about preferences beforehand, the surrogates’ decision making would be more accurate.

Natural, maybe — but wrong, according to the two studies that examined whether discussion improved accuracy.

One study found no change in accuracy, while the other found a slight but statistically significant worsening of surrogates’ accuracy after they talked with patients about their wishes.

“It was a little surprising that talking didn’t change accuracy, and we don’t really know

why that is,” says Wendler. “Our hypothesis is that the kinds of discussions you can have tend to be very general and not sufficiently rich to capture the complexity of real cases.”

Wendler says patients should be encouraged to think about what is important to them and what they envision happening in certain circumstances.

“A lot of time, it’s not clear,” he says. “If you like to talk, read, and walk, then would it be acceptable to you to be on a ventilator? Also, medical probabilities are involved [in real-life situations], and doctors can’t tell you what those are for sure.”

According to **Cynda Rushton**, DNSc, RN, FAAN, clinical nurse specialist in ethics at Johns Hopkins Children’s Center in Baltimore, a positive benefit to emerge from the Schiavo case is that the number of people who are considering the importance of designating health care agents and preparing living wills has jumped dramatically.

“We are encouraging living wills and for patients to converse with their surrogates early and often,” she says.

Rushton says a study conducted at Johns Hopkins, which examined the process of selecting and communicating with surrogates, found that while many had definite ideas they wanted surrogates to adhere closely to, others said they wanted family members to do what they thought was best under the circumstances.

Maryland is in the process of revamping its advance directives, to encourage people to indicate how they want their living wills interpreted — literally or by surrogates applying their best judgment at the time.

Wendler says surrogates were most accurate in making decisions in situations where the patient was in good health before becoming ill and the intervention was relatively sure to return him or her to good health.

“They’re good at predicting in those situations, because that’s easy,” he says. “If you’re a healthy 50-year-old and you get pneumonia and you need to be on a respirator but will recover, everyone will say ‘yes’ to that.

“The ones that give you trouble are the [exercises] where you start radically changing their cognitive state. That’s when the preferences aren’t as clear and surrogates misestimate it. But also, people have doubts about what their own preferences would be in those circumstances, for example, if they have Alzheimer’s.

“For me this suggests that we need more data on what people really care about,” says Wendler. “Argument points to using next of kin [for end-of-life decisions], but if you find out that the next of kin is not that accurate, then you have to ask yourself what the impact is for using family members as surrogates, and whether the impact is positive or not. Legislating [next of kin as surrogates] is a reasonable way to go, but you never know. These are hard decisions to make, and it may be a burden.” ■

Reference

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DM program helps AIDS patients

One-on-one education is the key to success

An intensive one-on-one case management program helps people with AIDS stay adherent to their medication regime, avoid hospitalizations and emergency department visits, and learn to self-manage their disease.

Positive Healthcare Florida, the disease management program of the AIDS Healthcare Foundation, is the only National Committee for Quality Assurance-accredited disease management program for HIV-AIDS in the country. The program received a score of 98.4% out of a possible 100% during the survey.

RN care managers with extensive HIV-AIDS expertise oversee the care of 10,000 Medicaid patients with AIDS across the state of Florida.

“We’ve been successful because of the intense one-on-one and face-to-face work with the patients. The nurses follow them closely and develop a wonderful rapport. The core of our program is education and one-on-one coaching to improve the patients’ quality of life and to keep them out of the emergency department and out of the hospital,” says **Gene Bundrock**, MS, RN, CCM, statewide director for AIDS Healthcare Foundation’s Positive Healthcare Florida.

The field-based care managers work out of their homes and manage the care of patients in the counties in which they live. They work closely with the patients’ physicians, often accompanying patients to their office visits, and working with them to coordinate care.

“Positive Healthcare takes a different approach to disease management. We do a lot of face-to-face assessments. The care managers get to know the provider and work closely with them. They meet with social service agencies in the community and incorporate them in the plan of care,” says **Donna Stidham**, chief of managed care for the AIDS Healthcare Foundation.

Publicly supported patients with AIDS present a challenge to providers. They are poor. Many don’t have telephones. They often live with relatives and move around a lot, Bundrock says.

The program uses representatives from the community who help find patients and call the care manager. The representative makes an appointment for the patient with the care manager, who sees him or her within three days.

“Our care managers will meet with them anywhere — the home, the doctor’s office, in a restaurant, or even under a bridge. We’ll go anywhere the patient feels comfortable and where their confidentiality won’t be breached,” Stidham says.

When new patients are identified for the program, the nurse contacts them and makes an appointment to see them, preferably at their home.

“It helps the nurses manage the care if they can see their patients in the home environment and become aware of their living conditions. Some don’t have electricity. Others may not have a refrigerator or cooking facilities. It helps us tailor a care plan when we can see firsthand what the patient is facing,” Bundrock says.

Patient assessments

The care managers conduct an extensive assessment that categorizes patients by severity level and acts as a guideline for the number of interventions the patient received. They determine the patients’ needs and barriers to care, such as transportation, and get a consent form allowing them to go into the physician’s office and examine the patient’s medical record.

"These patients are not good historians on previous hospitalizations. They may know they had a cough but not whether it was pneumonia. Our nurses examine the medical record to find out what we need to know to manage the disease," Bundrock says.

The care managers zero in on patients with a high acuity level who are frequently hospitalized, not adherent to their medication regime, and are substance abusers.

"Once the nurse has seen the patient in person, some of the work can be done telephonically. She might not need to see patients every month if they are doing OK, the lab work looks good, and she knows they are being adherent with their medications," Bundrock reports.

The disease management nurses remind patients if they have physician appointments, check to see that the appointment has taken place, and visit the physician's office to review the chart. They give the patient a pillbox to help them organize their medications and stress the importance of taking the medication until the physician discontinues it.

Because confidentiality is an issue with AIDS patients, Positive Healthcare mails AIDS-related educational materials only to patients who have given their permission. Otherwise, introductory and follow-up letters are very generic.

The care managers know their community well, often serving on local health planning councils. They know the practitioners in the community and know how to guide their patients through the complex medical system to get help.

The care manager can mine the database for claims data and talk to the physician if a patient is making frequent trips to the emergency department.

"These patients have a lot of mental health issues as well. Depression is a huge problem, and many are on psychiatric medication. Physicians can't get the patients interested in caring for themselves until their mental status is stable," Bundrock says.

Dental care is another problem for AIDS patients on Medicaid.

"The state doesn't pay for dental work of any kind, but Medicaid patients still get toothaches. We try to get them access to dental care so they won't go to the emergency department or hospital with an infection that's the result of a dental problem," he says.

A team of nurses and an LPN care partner manage the care of the population in each area. The LPN takes care of telephone calls and other reminders for patients who are at severity level 1, allowing the care manager to concentrate on the more complex patients who are in and out of the emergency department, helping them avoid admissions.

For instance, AIDS medications often cause adverse reactions until the patient gets used to them, causing trips to the emergency department for pain and nausea. The care managers encourage them to try alternatives.

Working with physicians

"Now instead of going to the emergency department when they start a new medication and have cramps, they call the care manager who helps them understand that it might be a side effect of the medication. They suggest that they use an over-the-counter medication rather than going to the emergency department," Bundrock explains.

The care managers work closely with the physicians and nurses in physician offices to make sure that the patients are getting the recommended care. They refer any problems they spot to Bundrock or the medical director, who contacts the physician and educates him or her about evidence-based guidelines for the treatment of HIV-AIDS.

Positive Healthcare holds six educational programs a year in each region, informing physicians about the latest information from the scientific community.

"We stay up on new treatment regimes and make sure the physicians know about them. A bad regime can have a bad outcome, which in turn can cost hundreds of thousands of dollars," Bundrock says.

Physicians in the AIDS Healthcare Foundation's disease management programs work with the physicians who care for the patient.

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"They don't want to interrupt the physician-patient relationship but they do want to enhance the physician's access to knowledge about the condition," Stidham says.

In California, the AIDS Healthcare Foundation began operating one of the first Medicaid managed care programs specially designed for people with AIDS in California in 1995. The foundation has received approval to operate a Medicare Advantage plan, allowing the patients to get their drugs through Medicare Part D.

The Medicaid program covers the sickest of the sick, only people with AIDS. HIV-positive patients are not eligible.

The state of California compares the foundation's costs to the fee-for-service Medicaid program and splits the savings with the foundation on a 50-50 basis.

"Our patients have always had better outcomes, shorter lengths of stay, and less cost than the fee-for-service patients," Stidham says.

Patients in both the Medicare and Medicaid programs are assigned an RN case manager who has HIV expertise. All of the primary care physicians and specialists in the network have experience working with people with AIDS, and the formulary is designed with people with AIDS in mind. ■

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